



A practical guide to caring



This guide has been prepared by NHS England, Age UK, CFOA, Carers Trust, Carers UK and Public Health England and older people themselves and contains general information which we hope will be of use to you.

Your individual case may well have specific circumstances that apply to it and so this guide should not be read as specific advice given to you, it should not be relied on as a basis for any decision or action you take in respect of the matters it covers and it should definitely not be used as a substitute for seeking specific advice from an appropriately qualified and experienced professional (generally, your GP).

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Who is this guide for?

The advice in this booklet will help you if you look after a friend or family member and/or have any form of caring responsibilities, but it is written to be particularly relevant for those who are about 65 years or older.

A carer is anybody who looks after a family member, partner or friend who needs help because of their illness, frailty or disability. The care they give is unpaid. Around 5.4 million people in England are caring for relatives and friends right now.

Caring for someone who is ill or disabled can help people live well at home and be part of their local community, but you also have to make sure you look after your own health and wellbeing too. The advice given here will provide hints and tips on how you can look after your own health as well as support the person you care for.



Case Study: Jeanette

Jeanette is 73 and cares for her daughter, Angela, who is 48 and has Down's syndrome, epilepsy and is profoundly deaf. Ten years ago Angela was also diagnosed with dementia.

Jeanette has cared for her daughter at home all her life.

Jeanette's typical day starts early helping her daughter up and to the toilet, she then prepares her breakfast, medication and drink. Jeanette then continues to care for Angela's needs throughout the day, keeping her physically and mentally stimulated. Angela's behaviour is very changeable and has become more challenging with the development of dementia. After a day of caring, Jeanette may be disturbed at night to tend to her daughter.

Jeanette has developed her own health problems, she had major heart surgery followed by a stroke and also has age related arthritis plus deafness too. Over time, Jeanette has learned about the **importance of taking regular breaks for her own wellbeing and that these are important for her and Angela**

What's it like caring for someone?



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Most of us will care for someone at some point in our lives when someone close to us becomes ill, frail or disabled – it might be your husband, wife or partner, son or daughter, parent or a close friend or neighbour.

Most people see caring as part and parcel of life. But caring can bring rewards as well as challenges that we're not always prepared for.

Caring for someone can help to give them the fullest life possible, but you have to make sure you look after your own health and wellbeing. This guide is designed to help get the best out of life for yourself and the person you care for.

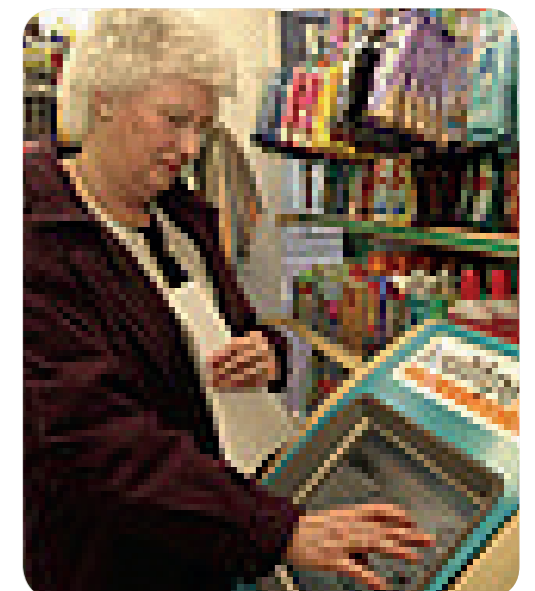
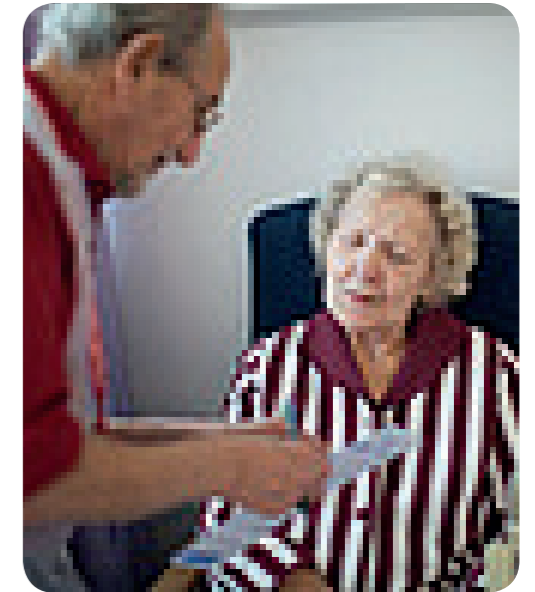
Caring for someone can start gradually and creep up on you, or it can happen overnight. Some people have a lifetime of experience of caring. Over time, carers often become experts in conditions and often understand the needs of the person that they know very well.

Systems and support can be complicated and difficult to understand. It's important that you find out what there is, how to cope with the challenges and look what support is available for you and the person you care for yourself. Usually, the more we know, the more we feel in control of our lives and the better we are able to cope and make the most out of life.

This guide can help you get the right support and information and make the most out of life.

As a first step it's important that you recognise that you are a carer. Even though you might see yourself as a wife, husband, brother or daughter, you are still caring for someone.

You are not alone. 1.2 million people aged over 65 in England are caring for relatives and friends right now.



Getting help



It is important to recognise you are a carer as there is information, support and advice that can help. Caring for someone can affect your own health and wellbeing, so getting help early is vital.

Common health issues associated with caring can be:

- Back and neck injuries
- Anxiety and depression
- Stress which can affect you physically with aches and pains, stomach complaints, as well as mentally with headaches and feelings of not being able to cope.

Do not put off going to the GP about your own health, getting advice and information early is vital. It will help you to keep yourself well and manage your caring situation. It may also help to prevent a crisis.

Carer's organisations can be enormously helpful offering a variety of emotional and practical support. They will know what is available locally to support you and the person you care for to continue to take part in social activities and hobbies, even take up something new. Keeping active and continuing with hobbies and friendships is not only enjoyable but good for your health.

Carer's services are run by a variety of organisations and what they offer does vary. They will all offer information, advice and guidance. They will help you to consider your own needs and inform you of your rights and entitlements as a carer.

Carer's organisations may also provide advice and information about:

- Support groups or information programmes
- Advocacy (helping you to get your voice heard)
- Respite and leisure opportunities (taking a break from caring see page 15)
- Help to plan for emergencies as well as the future
- Advice and support when someone is in hospital / ready to go home
- Small Grants for equipment or to take a break

It is important to look after yourself and getting in touch with a carers organisation early on in your caring role can help you receive the right support and information.

Other areas of support

If you are still at work and caring talk to your HR department or manager, let them know you are a carer. Carers have certain rights at work. (Insert link to carers uk fact sheet website).

Caring for someone with a long term condition or disability can be expensive, speak to your local carer's or disability support service to ensure you are receiving everything you are entitled to.

Local and national condition specific organisations such as the Alzheimer's Society, Stroke Association and MIND will be able to offer more expert advice on managing things like toilet problems, changing behaviour or depression and anxiety. (ref back for useful contacts).

You can find out more about help and support for carers from your local carers service and voluntary organisations at:

NHS Choices at www.nhs.uk/Service-Search

Carers Trust at www.carerstrust

Carers UK on **0808 808 7777** or visit their website:

www.carersuk.org/help-and-advice/get-support/local-support



Carer's assessments



Any carer who appears to have a need for support can be offered an assessment; this is usually carried out by the local social services department.

They can either speak to you separately or with the person you care for about how your situation affects your life and what help and support is available in your local area.

For the carer this is known as a carer's assessment.

- For the person being cared for this is known as a community care assessment
- Getting a community care assessment early on should give you access to local services which can help you and the person you care for keep well and feel supported.

There may also be other family members who help out and would like to be included, some examples of the kind of help that could be available directly to you as a carer:

- getting around: taxi fares, driving lessons, repairs and insurance, costs for a car where transport was crucial
- technology to support you: mobile phone, computer where it is not possible to access computer services from a local library
- help with housework or gardening
- help to relieve stress, improve health and promote wellbeing such as a gym membership

Your local social services department may or may not charge you for carer's services. However if they do decide to charge carers for services they must carry out a financial assessment to determine how much you would need to contribute (if anything).

If the person you care for does not want any help and support, you as a carer are still able to receive support, advice and information. Speak to your local carer's service for more information about what is available in your local area.

If things change it is important to ask for your situation to be looked at again to see what further help or support may be available. This can be done through a review of the carer's assessment and the care and support needs assessment.

The change may be:

- Related to the person you care for, for example their health or mobility may have deteriorated or their housing situation may have changed.

OR

- Related to you directly for example, you may have concerns about your own health, employment, finances or other family members.

For more information about carer's assessments, care support needs and financial assessments:

Call 0808 808 7777 or visit <http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

Looking after your own health



Carers often put their own health and wellbeing last, but that can have an impact on your health longer term and it's important that you look after yourself.

Staying well can be a real challenge but extremely important when you are caring for someone and when you are also trying to keep on top of your own life.

These are a few steps and services that you might find helpful:

- Tell your GP that you are caring for someone and ask them to mark it on your patient records so that they understand your circumstances and find it easier to offer the help and support you need
- Ask your GP about health checks, immunisation and screening programmes that are available to carers and older people which can help you protect and improve your health
- Sharing experiences and getting advice from other carers can be a lifeline. Local carer support groups or online forums can help
- Make sure you get regular breaks from caring (see page 8)
- There are tips on the Carers UK website that could help you get a better night's sleep. www.carersuk.org/help-and-advice/health/looking-after-your-health/getting-enough-sleep

There are things that can help to save time and improve your health and wellbeing:

- Check with the local pharmacy for services that might help: home deliveries, medication reviews, advice on medication can make life easier
- Does the person you are caring for consent to having health information shared with you? Make sure this is clearly recorded in their GP and hospital records so that doctors can involve you in decisions about their care
- Ask the GP and consultants and nurses about the condition of the person that you are caring for – often learning about a condition helps to understand and manage it better
- You can ask your GP or local carer group about getting help with transport to and from the GP practice or the hospital
- Can you do something online or by telephone instead of going in person – like access your patient record or get an appointment?



Health and wellbeing



When you are taking care of someone, it can be easy to forget to take care of yourself too.

Caring can be rewarding, but it can also have a significant impact on your physical and mental health and wellbeing. The Healthy Ageing Guide which complements this guide can provide you with more information and practical examples of how you can stay healthy.

Keeping healthy

There are simple steps you can take to ensure that your body and brain remain as healthy as possible as you age. They can also help manage existing health conditions you may have, and help you cope with pressures caring can sometimes bring.

- **Keeping active.** It's never too late to get active. You should aim for at least 150 minutes of physical activity each week, and undertake muscle strengthening and balance activities twice a week. But something is better than nothing; any physical activity for 10 or more minutes of at least moderate intensity (i.e. raises your heart and breathing rates) benefits your health. Think about activities you can coordinate with your caring or do it with the person you care for to both get active. Examples: brisk walking, cycling, swimming, yoga
- **Eating well and maintaining a healthy weight.** Consume a variety of foods high in fibre, vitamins and minerals, like fruit, vegetables and wholegrains. Try to reduce consumption of foods and drinks high in fat, salt and sugars. It's also important to keep hydrated – you should aim to drink 6-8 glasses of fluid a day.
- **Keeping alcohol consumption low.** Regularly drinking more than the recommended guidelines can damage your health. Men and women should not regularly drink more than 14 units of alcohol a week. This is equivalent to 6 pints of 4% beer, or 6 medium (175ml) glasses of 13% wine, spread over several days. One good way to cut down the amount you drink is to have several alcohol-free days each week.
- **Stopping smoking.** Even after many years, smoking is still worth stopping. Whatever your age, you can expect to see a range of benefits when you stop smoking. If you do smoke, it's important to protect the person you care for and those around you from second-hand smoke by never smoking indoors or in the car. **To quit, visit www.nhs.uk/smokefree, or call the smokefree helpline on 0300 123 1044.**



Coping with stress

Stress, anxiety and depression can affect anyone, but the pressure and expectations of caring can make carers particularly vulnerable. In turn make it very difficult to cope with the demands of caring.

Stress can affect your sleep and you can become more exhausted, tense, irritable and low. You can also feel as though you are losing control of your life and you have little way of regaining this control.

One of the first steps in dealing with stress is to acknowledge that it is happening and to think about the reasons. Starting to deal with the causes, even by taking very small steps, helps you feel more in control. The earlier you do this the better. Just talking about how you feel with someone can help you find a way to deal with it.

Dealing with depression

Depression is when you feel persistently low or sad and can't find any pleasure in life for weeks and months rather than just a few days. Many of us feel like this sometimes.

Depression is an illness, with real and sometimes frightening symptoms. It's not a sign of weakness or something you can 'snap out of' or deal with by 'pulling yourself together'. If you think you may be suffering from depression you should see your GP as soon as possible. Many people wait a long time before seeking help for depression from their GP. The treatment and support options for depression are very effective and the sooner you get help the sooner you can be on the way to recovery.

Keeping in touch and meeting people

Many carers sometimes feel lonely or socially isolated as a result of their caring responsibilities, which in turn impacts on their health. You may have found that caring has affected the relationship you have with the person you care for, as well as relationships you have with others.

Whilst caring responsibilities can make it difficult, it is important that you try to maintain your social connections as these are good for maintaining your own wellbeing. This may include keeping in touch with family and friends – even if it's just a quick phone call, joining online carer networks and visiting your local carers' service. It may also include taking a little time out to engage in any hobbies you may have and do the things that make you happy.

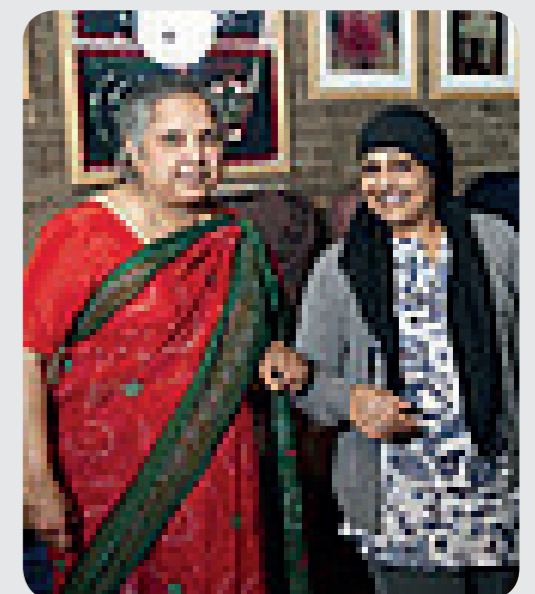
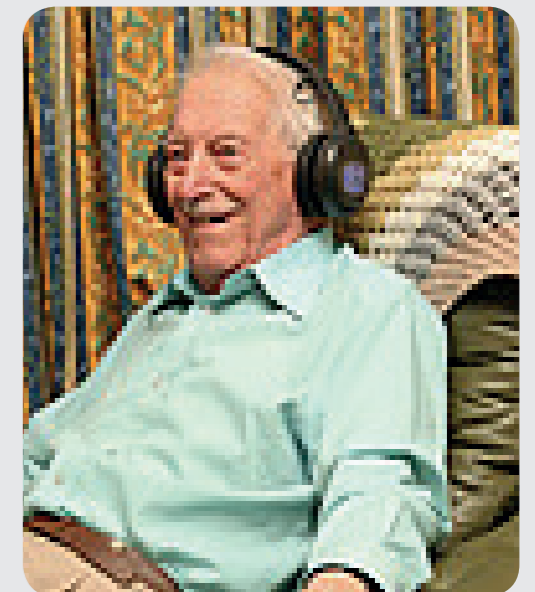
If you find that you don't have any time to do the things you enjoy, then it is important to find ways to take a break from your caring role (see page 8).

Acknowledging resentment and guilt

Like many carers, you may find yourself caught up in a cycle of resentment and guilt. You may no longer feel that your life is your own and may feel guilty for feeling that way. If this is something you are experiencing, it is important to acknowledge these feelings and not bottle them up.

It is normal to feel resentful that your life is not the one you imagined living or those things have changed. You may simultaneously feel that you should be doing more for the person you care for, or feel as though you aren't doing a good job.

It is important that you allow yourself to feel these perfectly normal feelings and not get overwhelmed by guilt. It is also important to try to find time to take care of your health and wellbeing, rest and re-energise, which may help you cope with some of these feelings.



Taking a break



When was the last time you took a break? Taking a break from caring is essential, it does not always mean time away from the person you are caring for. You can enjoy a break from the everyday together by attending local clubs, support groups and activities, visiting friends and family or taking a short break.

You might be able to arrange a break:

- Informally with help and support from family and friends
- Trying to make time for yourself
- It could be with the help of technology like telecare, giving you peace of mind. See page 10
- Formally through a carer's and/or a needs assessment for you and the person you care for. Having a carer's assessment would help identify the type of break which will be helpful to you
- If you are concerned about funding for a break contact your local carer's ??????? for further information and advice

You can take a break and have emotional support together or separately. A break away from the demands of caring is as important as a rest from the physical demands of the role. Talk to the person you care for and plan regular breaks.

You may be able to get support with arranging a break from your caring role through an assessment of you as a carer or the person you care for. Or you may decide to arrange the extra care and support yourself. Sometimes breaks are called respite care. This is a usually replacement care and support for the person you care for, which can also give you a break from caring.

As the aim is to give the carer a break from caring to enable them to do something for themselves, this is called a "carer's break". These are usually tailored to a carer's needs which are identified in a carer's assessment.

Here are some examples of breaks that carers have said they value:

" We use a holiday company specialising in people with disabilities so we can have a break away from everyday life and meet other people. "

" Fortnightly I visit the local memory café to meet other people. "

" We go to the gym or for a swim together, my husband has dementia but is still quite active (most local pools have sessions for older and disabled people.) "

" A week away once a year when my daughter goes into respite, she loves the break too. "

" My local church is opposite my house so I feel confident enough to pop over and leave my husband for an hour. "



Contact your local carer's service for information on breaks and carer's support groups..

www.carers.org/carers-services/find-your-local-service

www.carersuk.org/help-and-advice/get-support/local-support

Making better use of technology



Technology has become an important part of everyday life and can make life easier for carers in many ways. It can be helpful to know what technology is available to help you, where you can find it, and how you can access it.

As a carer you can use the internet to help manage your health and that of the person you care for by booking GP appointments and ordering repeat prescriptions online. Ask the practice receptionist how to do this.

If your GP recommends that you or the person you care for should see a consultant they may tell you about the e-referral system. This online system allows you to book an outpatient appointment at the hospital of your choice for a day and a time that suits you.

For more information you can access:

www.nhs.uk/choiceintheNHS/Yourchoices/appointment-booking/Pages/about-the-referral-system.aspx

If your GP wants to keep an eye on your blood pressure they can now give you equipment that automatically sends the results back to the surgery.

There are other technological devices that can give you peace of mind to leave the house or get a good night's sleep, confident that you will be informed if an emergency occurs. These devices can also give the person you care for greater independence. This type of support is known as telecare.

Some examples of telecare devices which are being used to transform the lives of carers and those they look after are:

- Sensors that can detect if the gas has been left on or if someone has got out of bed
- Wearable technology such as a wrist alarm that allows you (the carer) to be alerted if a serious fall is detected

If you think this type of support would be helpful, raise it when the person you care for has their needs assessment or during your carer's assessment or contact your local social services department and ask for information about their telecare services. If you are interested in purchasing technological devices and equipment, talk first to your local carer's service to find out if there is any financial support available to assist you.

For more information and examples of technology support visit the Carers UK Website at www.carersuk.org/help-and-advice/equipment-and-technology.

You can also use the internet to save time, keep in touch with friends, family and other carers and to enjoy some 'me' time by:

- Shopping for food (and other things) for home delivery
- Online banking
- Joining an online carer's forum
- Keeping in touch with family and friends by email, Skype, Facebook or WhatsApp
- Sharing photos
- Using websites to find information and even research your family history
- Keep your mind active by playing games online like Scrabble or Patience

For further information about getting online, making the best use of using the internet and technology you can go to: www.ageuk.org.uk/work-and-learning/technology-and-internet/

Age UK also provides guides that will help you get started, stay safe online and make the most of the internet. Why not find out if there is a local Age UK offering computer training courses in your area by calling Age UK Advice on 0800 169 6565 for the number of your local Age UK or Visit Age UK website

Multiple health conditions and caring



When we get older, we often develop several conditions, not just one. For example, someone who has had a stroke might also have high blood pressure and diabetes.

This, combined with the fact that our personalities and wishes are all different, makes every caring situation different.

As time goes on, people can often become experts in their conditions and they say that this helps feel like they are more in control of the condition and manage it better.

Step 1:

Find out about different conditions. The NHS Choices website is a good place to start with lots of information about conditions. Your GP will be able to tell you more too, especially if you don't have access to the internet. You should also discuss with your GP about your care and support plan to make sure you and the person you care for are getting the care and support you need.



Step 2:

If you or the person you care for has several different types of medication, it is useful to get a medications review and see what other services your pharmacy has to help with medication.



Step 3:

There are often different support groups where you can find information about the different conditions e.g. local dementia support cafés, MS clubs, but there are also services run for all carers of people with all conditions run by local carers' organisations, and Age UK also runs services for older people.

Where can you start finding out about conditions:

<http://www.nhs.uk/pages/home>

British Heart Foundation: 0300 330 3311

Alzheimer's Society: National Dementia Helpline 0300 222 1122 www.alzheimers.org.uk

Rethink Mental Illness: 0300 5000 927

Stroke Association: 0303 3033 100

Preparing for the end of caring



Everyone's caring journey is different – some people recover from an illness and go on to lead fulfilling lives. For others, caring can become too much and for some, it is caring at the end of life.

Whatever our experience of caring, thinking about what happens if you are no longer to care anymore, or what will happen when the person you care for dies, can help you be ready for the future.

When caring gets too much:

More care and support

If you are not able to care as much anymore, you may be able to get more care and support in the home or technology might be able to help.

Residential care

If this is still not enough, you might consider that residential care is the right option. There is lots of good advice about how to choose a care home, what to look for and, importantly, how much it might cost. It's really important to get good advice. Ref to Age UK. Care homes welcome spouses, partners, relatives and friends into the home to visit and also encourage activities together.

End of life and bereavement

If caring is coming to an end because someone is about to die, then there is additional care and support that you may be able to have. Many people want to die at home and families caring for them help that to happen, so it's important that you get good information and support.

Marie Curie Cancer Care provide a really good guide to the end of life: www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/being-there-for-someone/preparing-for-the-end-of-life/end-of-life-guide.pdf

This booklet also looks at many of the practical things that need to be considered and done which can be stressful, at a time of grief.

<http://www.carersuk.org/help-and-advice/practical-support/when-caring-ends>

Rebuilding your life

There is a time when you need to start thinking about rebuilding your life and this is where community groups are a good place to start, or think about volunteering.

